

Life Opportunities Survey

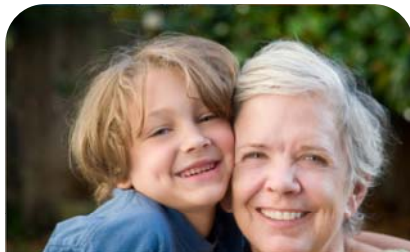
User guide to defining and coding disability¹

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Introduction

A variety of definitions of disability can be coded from the Life Opportunities Survey (LOS). This paper discusses how the LOS data can be used to produce a range of key disability estimates.

Defining Disability

This section outlines the approach taken by the LOS for defining disability. The definitional challenges are discussed through a summary of the main conceptual models of disability. The approach taken was to design a survey which is compliant with the social model and provides a robust data source for understanding the multi-dimensional and dynamic nature of disability.

Conceptual Models of Disability

The Medical Model

This approach to disability locates the problem within the individual. The medical model defines disability with reference to what is 'wrong' with the person, and how they are thought to differ from what is 'normal'. The focus is on curing or caring for disabled people, with the implication that the way to overcome barriers to inclusion is to alter the individual to 'fit' better into society.

Early attempts by the World Health Organisation (WHO) to standardise concepts and definitions resulted in the International Classification of Impairments, Disabilities and Handicaps (ICIDH) in 1980. This definition underlies the OPCS surveys of disability (Martin et al. 1988), which define disability as 'a restriction or lack of ability to perform normal activities, which has resulted from the impairment of a structure or function of the body or mind'.

The Social Model

This approach challenges the underlying assumptions of the medical model. Disability, rather than being viewed as an attribute of the individual, is repositioned, as the disadvantage, or restriction of social participation, caused by aspects of society which take little or no account of the needs of people with impairments. This is described in the "Improving Life Chances of disabled people report"¹ as follows:

¹ PMSU.2005: <http://www.cabinetoffice.gov.uk/media/cabinetoffice/strategy/assets/disability.pdf>

“Disability should be distinguished from impairment and ill health.....disability is defined as: disadvantage experienced by an individual resulting from barriers to independent living or educational, employment or other opportunities that impact on people with impairments and/or ill health.

A clear distinction needs to be made between disability, impairment and ill-health. Impairments are long-term characteristics of an individual that affect their functioning and/or appearance. Ill health is the short term or long-term consequence of disease or sickness. Many people who have an impairment or ill health would not consider themselves to be disabled.”

The Life Opportunities Survey adheres to this model in its design and reporting. Data is collected on impairments but unlike the previous OPCS surveys this is not equated with disability status. The survey explores the barriers to life opportunities that people both with and without impairments face and then assesses the extent of additional disadvantage experienced by people with impairments due to the range of social barriers, discrimination or lack of support, assistance and adjustments.

ICF: The Biopsychosocial Model

The International Classification of Functioning, Disability and Health (ICF) was developed by the World Health Organisation (WHO) in response to the social model's critique of the ICIDH. ICF attempts to bridge the gap between the medical and social models through the inclusion of the social context of disability. The ICF guide (WHO 2001) states:

“Previously, disability began where health ended; once you were disabled, you were in a separate category. We want to get away from this kind of thinking. We want to make ICF a tool for measuring functioning in society, no matter what the reason for one's impairments.

Disability is always an interaction between features of the person and features of the overall context in which the person lives, but some aspects of disability are almost entirely internal to the person, while another aspect is almost entirely external. In other words, both medical and social responses are appropriate to the problems associated with disability; we cannot wholly reject either kind of intervention.”

In developing the LOS questionnaire, we learned from the extensive international work that has been carried out to implement the ICF in other countries². This has been useful for standardising international comparisons on outcomes for people with impairments, which is of increasing importance

² See UN Statistics Division:

<http://unstats.un.org/unsd/methods/citygroup/washington.htm>

following the UK's ratification of the UN Convention of Rights of Disabled People. Our methods of classifying impairments are compatible with this approach.

Some countries³ which have adopted the ICF framework have however defined disability through severity of impairment and the language used, such as “having a disability” locates ‘disability’ as an attribute of the individual, similar to impairments. As outlined above, in the analysis of the LOS, we do not equate disability status with prevalence of impairment alone. Through involvement of a Reference Group of disabled people, we have considered the social and environmental topics outlined in the ICF Framework and developed, expanded and tailored these to the common social barriers faced in Britain. The ways in which disability is measured in the LOS are detailed below.

The approach used in the LOS

The LOS follows the social model's definition of disability as the social disadvantage experienced by people with impairments. For the purposes of the LOS, disability is conceived as the interaction between impairments (either of body functions or structures) and social/contextual factors. In order to measure the underlying factors associated with disability, it is important to collect data on these constructs independently and thereafter explore associations and causal links between them.

How much information do we need about impairments?

Following the social model definition, it is the barriers to participation which are of interest, regardless of the nature or severity of the impairment. However, Berthoud (2003) and Grundy et al. (1999) demonstrate that the experience of disability varies considerably by severity. Burchardt (2003) argues that the absence of direct information on the severity of impairment is a significant drawback to survey data, because ‘by grouping disabled people together, and comparing to the non-disabled population, we are likely to understate the disadvantage faced by people with severe impairments’ (p. 8). This view is outlined in the “Improving Life Chances” (2005) report:

“There are large differences in impairment experienced by disabled people. Because of this, generalisations are often unhelpful. Disabled people with different impairments, from different socio-demographic backgrounds and facing different barriers will have very different day-to-day experiences”.

We therefore collect some basic information about the severity of impairment alongside experiences of social barriers and participation restrictions. In line

³ For example, see “Living with Disability in New Zealand”:
<http://www.moh.govt.nz/moh.nsf/pagesmh/3532>

with the ICF, severity of impairment is defined through respondent's reported ability to perform certain physical or mental functions, such as seeing, hearing, walking etc and any level of difficulty with associated daily activities, such as reading a newspaper or climbing stairs.

Defining groups

In ICF terminology the LOS will compare the experiences of people with impairments against people without impairments, and explore the participation restrictions of both groups. The LOS does not equate having an impairment with being disabled. A person may have some form of impairment without having any activity limitation and may not be considered or consider themselves as disabled. Following the social model, disability is understood as the disadvantage people with impairments experience due to barriers that restrict their participation in different areas of life. To meet the social model definition of disability, the LOS requires someone to have experienced barriers to participation and have an impairment.

To clarify the approach the LOS has taken at the analysis stage, respondents have been defined according to the following four scenarios:

1. People with impairments who face participation restrictions
2. People with impairments who do not face participation restrictions
3. People without impairments who face participation restrictions
4. People without impairments who do not face participation restrictions

Only people in scenario one will be considered to be disabled using the approach described above.

In the baseline survey (wave one) all adults who agree to take part from a random sample of around 37,500 households will receive a full face to face interview (whether they have an impairment or not). As a longitudinal survey, the LOS is designed to follow-up every respondent on an annual basis. Part of the longitudinal design of the survey involves categorising respondents into three main sample groups for follow-up in future years (or Waves of interview).

- Group A – people with impairments at the baseline survey
- Group B – a sub-sample of people without impairments who will act as a comparison sample to compare outcomes with Group A
- Group C – the remainder of the sample of people without impairments, who will be followed by telephone to identify whether they have experienced onset of any impairments. If so, an interviewer will call at the household to carry out the full face to face interview

Disability Discrimination Act (DDA) and Equality Act 2010

In addition, an estimate of people with rights according to the Disability Discrimination Act 1995 (DDA) is provided. Section 1(2) of the DDA generally defined someone as disabled if “he or she has a physical or mental impairment which has a substantial and long-term adverse effect on her or his ability to carry out normal day-to-day activities”. From 1 October 2010, provisions in the Equality Act 2010 (EA) replaced the majority of provisions in the DDA. In general, the definition of disability in the EA is similar to that which applied for the purposes of the DDA. Unlike the DDA, it does not require a disabled person to demonstrate that, where their impairment adversely affects their ability to carry out a normal day-to-day activity, that activity involves one of a specified list of capacities, such as mobility, speech, or the ability to understand.

The Disability Equality Duty 2006 (DED) is part of the DDA 2005 and requires public authorities to pay due regard to disability issues when carrying out their functions. Its accompanying codes of practice provided good practice guidance on how government departments and other public bodies can meet the DED and assess the impact of their policies and services on disabled people and measure progress towards disability equality⁴.

The DDA definition of disability has therefore been the starting point for several government sponsored surveys, such as the Family Resources Survey⁵, in order to assess outcomes for people with rights under the legislation. The LOS has also included a short suite of DDA definition questions, which will allow comparison of statistics on outcomes for disabled people with other surveys.

As a longitudinal survey, the LOS will allow analysts to monitor outcomes for disabled people through future years using the social model based approach outlined above. Inclusion of the DDA definition questions will also allow for important comparisons in outcomes for disabled people by using time series data from other surveys over previous years.

Coding Disability

This section sets out how the various aspects of disability can be coded from the LOS questionnaire. A guide to the LOS wave one questions is provided in appendix 1. The language of the ICF is used (see section 2.2 for key definitions). The ICF also provides a coding scale, described in appendix 2.

⁴ <http://www.dotheduty.org>

⁵ For further information about the Family Resources Survey see: <http://statistics.dwp.gov.uk/asd/frs/>

Coding ICF outputs

Impairments and Activity Limitations

Impairments relate to the loss of physiological and psychological functions of the body such as loss of sight, hearing, mobility or learning capacity.

Impairments should be distinguished from medical conditions or loss of bodily structure. For example glaucoma is a medical condition. Loss of vision is the impairment it causes. Activity limitations are restrictions an individual may have in executing physical or mental tasks or actions as a result of their impairment, for example, being unable to read newsprint at arms length without glasses or other aids and adaptations.

Measuring activity limitation and impairment takes into account the fact that not all conditions will result in limitation of the range of daily activities one can do. The LOS therefore contains separate questions on physical and mental health conditions to questions on impairments and activity limitation in order to make clear theoretical distinctions between these concepts.

Questions that would feed into the impairments and activity limitation output are found in the 'impairments' section of the LOS questionnaire, in particular the questions asking what level of difficulty the respondent has in carrying out an activity and how often an impairment limits the kind or amount of physical or mental activities an individual can do.

Table 1 **Impairment cut-off points**

If...	is greater than...	and...	is more often than 'never', then the respondent has...
SeeClo or SeeDis	mild difficulty	SeeLim	an activity limitation in relation to a visual impairment
HearB	mild difficulty	HearLim	an activity limitation in relation to a hearing impairment
SpkDiff	mild difficulty	SpkLim	an activity limitation in relation to a speech impairment
MobA	mild difficulty	MobLim	an activity limitation in relation to a mobility impairment
DexDiff	mild difficulty	DexLim	an activity limitation in relation to a dexterity impairment
PainLev	mild	PainLim	an activity limitation in relation to a pain impairment
CondDiff	mild difficulty	CondLim	an activity limitation in relation to a chronic health condition
BrthDif	mild difficulty	BrethLim	an activity limitation in relation to a breathing impairment
LrnDif	mild	LrnLim	an activity limitation in relation to a learning impairment
IntelDif	mild	IntelLim	an activity limitation in relation to an intellectual or developmental impairment
BevDif	mild	BevLim	an activity limitation in relation to a social or behavioural difficulty
MemDif	mild	MemLim	an activity limitation in relation to a memory impairment
MenDif	mild	MenLim	an activity limitation in relation to a mental health impairment
OthDif	mild	OthLim	an activity limitation in relation to an other impairment

Participation restrictions

This area of the ICF covers the barriers an individual may experience in participating in life situations. Participation restrictions may be related to an impairment or activity limitation, for example someone with a mobility impairment may be prevented from finding a suitable job because an employer has not made reasonable adjustments. Alternatively, participation restrictions may be due to factors unrelated to impairment, for example someone may be too busy with family responsibilities to take up work.

An output based on this area alone is not an output of 'disability', since it will pick up on the restrictions of both impaired and non-impaired people. It is more akin to an index of social disadvantage, regardless of impairment status. However, combined with information on impairments, this output is essential for producing social model analysis.

Questions that would feed into to this area are found throughout the main sections of the LOS questionnaire.

Table 2 Life areas that feed into participation restriction measures

Variable...	indicates a participation restriction relating to...	ICF code⁶
Learn	Education	d810 - d839
Work, Seek, NoWrk	Work and Employment	d840 - d859
EndsMeet	Economic Life	d870
VclOut, VclMuch	Using private motorized transportation	d4701
LBus, LTrain etc.	Using public motorized transportation	d4702
LifeOppA, LifeOppB	Community, leisure and civic life	d910 - d950
GetHome, InOut	Moving around within the home	d4600
IntoBld, ThruBld	Moving around within buildings other than the home	d4601
CloseNum, MeetNum, MeetOft	Interpersonal interactions and relationships	d710-d799

In some cases, the follow up questions on contextual factors will need to be examined, in order to filter out cases where a respondent doesn't participate in an area of life because they simply don't want to. For example when asked 'what is stopping you from going to museums or places of historical interest', respondents can choose 'do not want or need to'.

Coding DDA outputs

A suite of questions to capture DDA disability have been included in the LOS questionnaire which enables analysis of the number of individuals that are likely to have rights under the act. The LOS DDA output will provide a useful comparison with other surveys which include the DDA questions, for example

⁶ See appendix 2 for more information about using the ICF coding scale.

the Family Resources Survey (FRS), as well as the ability to compare the DDA population against the LOS social model definition of disability.

Combining responses to the DDA questions as indicated in the table 3 below will allow calculation of the number of individuals with rights according to the Disability Discrimination Act.

Table 3 Coding of DDA questions

Question	Response
Health	Yes, i.e. individual has a long-standing physical or mental impairment, illness or disability.
DisDif	Individual responds as having a substantial difficulty in one or more area of their life, i.e. DisDif1=Yes or DisDif2=Yes or DisDif3=Yes or DisDif4=Yes or DisDif5=Yes or DisDif6=Yes or DisDif7=Yes or DisDif8=Yes or DisDif9=Yes.
DDATre	Yes, individual received medication or treatment without which their health problems would substantially affect their life in the areas identified within the DisDif question.
DisDifP	Yes, individual has had a long-term physical or mental impairment, illness, or disability that affected their activities. Where long-term is defined as lasting for a year or more. AND
DDATreP	Yes, the health problem or disability identified at DisDifP substantially limited their ability to carry out normal day-to-day activities. If medication or treatment was received the respondent was asked to consider what the situation would have been without medication or treatment.
DDAProg	Yes, the individual has been diagnosed with HIV, Cancer or Multiple Sclerosis.

It should be noted that the FRS measure of individuals that are DDA disabled excludes the progressive illness question (DDAProg), however, it will be possible to produce comparable outputs from the LOS. LOS estimates on the prevalence of DDA defined disabled people are based upon people who are currently disabled.

Overall Disability Prevalence Rates

Bajekal et al. (2004) conclude that 'it is critical that users of disability estimates understand how certain differences are generated'. It is possible that a range of estimates could be published. However, one of the key outputs

is an overall prevalence rate of disability, understood in the traditional sense as 'impairment'.

However, an important aim of the LOS has been to produce estimates based on a more up-to-date definition of disability; in particular, one which draws from the social model and the ICF.

Comparative approach

A social model output has been constructed using a comparative technique, where the participation restrictions of people with impairments are compared with those without impairments. An adult has a participation restriction if they experience at least one social barrier to taking part in at least one of the following life areas:

- education and training
- employment
- economic life and living standards, for example being able to afford expenses or make loan repayments
- transport
- leisure, social and cultural activities
- social contact
- accessibility of housing
- accessibility outside the home

Examples of social barriers include: discrimination; the attitudes of other people; inaccessible buildings, public transport and information; limited income; not having anyone to meet or speak to; as well as lack of support, equipment and adjustments.

The social model output provides an overall indicator of the prevalence of social model disability, but will also lends itself well to longitudinal analysis; we would expect the difference in participation restrictions between impaired and non-impaired people to reduce as the Governments commitment to disability equality is achieved⁷. Table 4 shows participation restriction prevalence by life area and impairment status in Great Britain between June 2009 and March 2010.

⁷ See the Governments business plan: <http://transparency.number10.gov.uk/transparency/srp/view-srp/42/81>

Table 4 Prevalence of participation restrictions of adults by life area and impairment status, 2009/10

Area of participation	Adults without impairments	Adults with impairments	Ratio
Education and training	9%	17%	1.8
Employment	26%	56%	2.2
Economic life and living standards	29%	45%	1.5
Transport	58%	74%	1.3
Leisure, social and cultural activities	78%	83%	1.1
Accessibility outside the home	7%	29%	4.2
Social contact	22%	24%	1.1
Total	84%	93%	1.1

The final column is calculated as the level of participation restriction of those with impairments divided by the level of participation restrictions for those without impairments. This provides an indication of the inequality experienced by people with impairments. For example, those with impairments are more than twice as likely to experience participation restrictions in education. The total of this column is the ratio for all participation areas, which will provide an indication of the prevalence of social model disability in Great Britain. This can be tracked longitudinally.

While stand-alone outputs for each of the domains is relatively straightforward to produce, more complex analysis will be called for to examine the relationship between impairments, activity limitations and participation restrictions, and thereafter to understand how contextual factors influence these.

Participation Restriction Index

An additional social model approach is to add together the number of barriers a person with an impairment faces. A Participation Restriction Index (PRI) has been constructed, calculated from the sum of participation restrictions. All individuals, regardless of impairment status, have been given a PRI score. Comparing the PRI of impaired vs. non-impaired respondents gives an indication of the participation inequality faced by people with impairments. Please see chapter 3 of the LOS Interim Report, 2009/10, for further information about the participation restriction index and methodology.⁸

⁸ The Life Opportunities Survey Interim Report, 2009/10, can be found at: <http://www.statistics.gov.uk/statbase/Product.asp?vlnk=15386>

Impairment cut-off points

Impairment status is defined from responses to the Impairments and health conditions section of the LOS questionnaire. The approach we have taken is similar to the Northern Ireland Survey of Activity Limitation and Disability (NISALD)⁹, which uses a similar set of impairment screener questions. A respondent is defined as having an impairment if they indicated the following within the impairments and health conditions section of the questionnaire:

- they experience either moderate, severe or complete difficulty within at least one area of physical or mental functioning, and
- certain activities are limited in any way as a result. 'Activities' refer to different areas of physical or mental functioning, such as walking, climbing stairs or reading a newspaper¹⁰

It is therefore possible for adults to have more than one impairment. The survey includes questions about physical, mental and long term health conditions.

Severity of impairment

Severity of impairment is defined from responses to the Impairments and health conditions section of the LOS questionnaire. Respondents with impairments have been ranked into a severity category of one to four (with one being least severe and four being most severe). This has primarily been based on responses to questions asking about respondent's level of difficulty in each of the 14 areas¹¹ of physical or mental functioning. For example, their reported level of difficulty with climbing stairs, reading a newspaper at arms length or remembering things.

In recognition that people have fluctuating impairments with different levels of frequency, the classification of severity of impairment has also taken into account the frequency of activity limitation. For example, whether the respondent has difficulty with activities related to mobility; rarely, sometimes, often or always.

To give an example: a respondent with a mild level of difficulty with activities related to mobility, which they experienced 'rarely', 'sometimes' or 'often' would be coded into severity category one. Respondents with a mild level of difficulty with mobility that they experienced 'always' are coded into severity category two.

⁹ Northern Ireland Statistics and Research Agency, 2007, *The Prevalence of Disability and Activity Limitations amongst adults and children living in private households in Northern Ireland*

¹⁰ This differs from the NISALD impairment definition as those who have indicated that they had a number of mild difficulties with each limiting their activities 'sometimes' are excluded.

¹¹ Sight, hearing, speaking, mobility, dexterity, long term pain, breathing, learning, intellectual, behavioural, memory, mental health condition, chronic health condition, other impairment or health condition.

A summary of how the severity score has been defined is given in the table 5 below.

Table 5 Severity score ranking

	Frequency			
Difficulty	Rarely	Sometimes	Often	Always
Mild difficulty	Category 1	Category 1	Category 1	Category 2
Moderate difficulty	Category 1	Category 2	Category 2	Category 3
Severe difficulty	Category 2	Category 3	Category 3	Category 4
Cannot do	Category 3	Category 4	Category 4	Category 4

For more information about the derivation of the severity score please see chapter 19 of the LOS Interim Report 2009/10.¹²

¹² The Life Opportunities Survey Interim Report, 2009/10, can be found at:
<http://www.statistics.gov.uk/statbase/Product.asp?vlnk=15386>

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Appendix 1: LOS question guide (wave 1)

Question	Purpose	Background	Testing	Used for PRI
ICF Participation Restrictions				
ICFLim	To provide a high level indicator of ICF 'participation restriction'. These questions have been designed so they can be administered by proxy if necessary. (ICF codes d810-d839, d840-d859, d450-d489, d710-d779, d920)	These questions were designed to compliment the harmonised disability questions, which measure impairment rather than participation restrictions. While the LOS questionnaire provides a much more detailed measure of participation restriction, including ICFLim alongside the rest of the questionnaire means we can see how the questions relate. This will mean any other survey using these questions can be compared to LOS.	No qualitative testing as of Jan 09. Proposed to be tested alongside disability harmonisation project. Was run on the February Pilot.	Yes
ICFWhy	This is a follow up to ICFLim, and records various contextual factors (environmental and social barriers) which may be contributing to a participation restriction.	Health condition/disability are also included, as under the ICF, body functions and structures interact with contextual factors in the process of participation restriction. In addition, testing has shown people with impairments or health conditions will often want to answer in this way.	No qualitative testing as of Jan 09. Proposed to be tested alongside disability harmonisation project. Was run on the February Pilot.	Yes
ICFChild	This is a variation of ICFLim. The only difference is that 'Work' has been replaced with 'Leisure or Play', but the purpose is the same. (ICF-CY codes d810-d839, d920, d450-d489, d710-d779)		No qualitative testing as of Jan 09. Proposed to be tested alongside disability harmonisation project. Was run on the February Pilot.	Yes
ICFWhyC	This is a follow up to ICFChild - there are no differences in its purpose or wording.		No qualitative testing as of Jan 09. Proposed to be tested alongside disability harmonisation project. Was run on the February Pilot.	Yes
Learning				
Learn	Record whether there are any barriers to learning, or in ICF language	This question hasn't changed much since the first draft, although some minor changes were made following	Qualitative testing, feasibility trial and pilot.	Yes

	'participation restrictions' to learning. (ICF code d810-d839)	qualitative testing.		
LearnLim	This is a follow up to Learn, and records various contextual factors (environmental/social barriers and personal factors) which may be contributing to a participation restriction.	The list of contextual factors has been designed through consultation with the RADAR reference network of disabled people. These are some of the most common reasons given by RADAR members. They have also been qualitatively and quantitatively tested. Health condition/disability are also included, as under the ICF, body functions and structures interact with contextual factors in the process of participation restriction. In addition, testing has shown people with impairments or health conditions will often want to answer in this way.	Qualitative testing, feasibility trial and pilot.	Yes
SEN, SenCurr	Record special educational needs of children aged 11 to 15.	These questions have been included due to a request from a government department. Taken from the Longitudinal Survey of Young People in England (2004)	None of our own qualitative testing, although LSYPE may have done some. Was run on the February Pilot.	No
Work				
UsuHr	Record number of hours worked. This can be compared with number of hours spent caring for others.		Harmonised question, so we did not include in qualitative testing. Was run on the feasibility trial and pilot.	No
Work, Seek, (NoWrk)	Record whether there are any barriers to employment, or in ICF language 'participation restrictions' to employment. Questions are routed to according to employment status. (ICF code d840-d859)	Most people are limited in the work they can do to some extent because of the qualifications needed to do some work. However, looking at the responses to the follow-up questions will tell us more about why people feel they are limited.	Qualitative testing, feasibility trial and pilot.	Yes
WorkLim, SeekWhy, NoWrk	These record various contextual factors (environmental/social barriers and personal factors) which may be contributing to a participation	The list of contextual factors has been designed through consultation with the RADAR reference network of disabled people. These are some of the most common reasons given by RADAR members. They have also been	Qualitative testing, feasibility trial and pilot.	Yes

	restriction to working.	<p>qualitatively and quantitatively tested.</p> <p>Health condition/disability are also included, as under the ICF, body functions and structures interact with contextual factors in the process of participation restriction. In addition, testing has shown people with impairments or health conditions will often want to answer in this way.</p>		
WorkHelp, SeekHelp, NoWkHelp	Record where facilitators have helped people to work, or would be needed by someone to be able to work.	Facilitators are the opposite of barriers. These questions were added at the request of HMRC.	Feasibility trial and pilot only.	No
Economic Life				
RepayL, BurdRepyL, AffordL	Provide a comparable measure of financial difficulty / material deprivation.	ODI requested that we include something on material deprivation. These questions were designed for GLF in order to meet an EUSILC requirement. They have not been qualitatively tested by GLF or by LOS.	Feasibility trial and pilot only.	No
EndMeet	Record the level of difficulty people have managing financially. The purpose is similar to other barrier questions, in that it records whether there are any participation restrictions to 'economic life'. (ICF code d860-d879)		Feasibility trial and pilot only.	Yes
MonRL	This is a follow up to EndMeet, and records various contextual factors (environmental/social barriers) which may be contributing to financial difficulties.		Feasibility trial and pilot only.	Yes
Transport				
UseVcl	Record whether anyone in the household has use of a motor vehicle. This is used as a filter for the following questions.	This is a GSS harmonised question.	Feasibility trial and pilot only.	No
VclOut,	Record whether there are any barriers	If the respondent says they don't go out in the vehicle, or	Qualitative testing, feasibility	Yes

VclMuch	to using a motor vehicle, or 'participation restrictions' to using a motor vehicle. (ICF code d470-d489)	that they go out less than they would like, there may be a barrier so the follow up question (TranStp) is asked.	trial and pilot.	
TranStp	Record various contextual factors (environmental/social barriers and personal factors) which may be contributing to a participation restriction to using a motor vehicle.	<p>The list of contextual factors has been designed through consultation with the RADAR reference network of disabled people. These are some of the most common reasons given by RADAR members. They have also been qualitatively and quantitatively tested.</p> <p>Health condition/disability are also included, as under the ICF, body functions and structures interact with contextual factors in the process of participation restriction. In addition, testing has shown people with impairments or health conditions will often want to answer in this way.</p> <p>If a respondent indicates that the only reason they don't use this mode of transport is that they don't want or need to, then they should not be recorded as having a participation restriction/barrier.</p>	Qualitative testing, feasibility trial and pilot.	Yes
LBus, LBusMuch, DBus, DBusMuch, UndTr, UndMuch, LTrain, LTraMuch, DTrain, DTrainMuch, Taxi, TaxiMuch	Record whether there are any barriers to using modes of public transport, or 'participation restrictions' to using modes of public transport. Six different modes of transport are distinguished. (ICF code d470-d489)	If the respondent says they don't use a mode of transport, or that they use it less than they would like, there may be a barrier so a follow up question is asked.	Qualitative testing, feasibility trial and pilot.	Yes
TrLBus, TrDBus,	Record various contextual factors (environmental/social barriers and	The list of contextual factors has been designed through consultation with the RADAR reference network of	Qualitative testing, feasibility trial and pilot.	Yes

TrUnd, TrLTra, TrDTra, TrTax	personal factors) which may be contributing to a participation restriction to using a motor vehicle.	<p>disabled people. These are some of the most common reasons given by RADAR members. They have also been qualitatively and quantitatively tested.</p> <p>Health condition/disability are also included, as under the ICF, body functions and structures interact with contextual factors in the process of participation restriction. In addition, testing has shown people with impairments or health conditions will often want to answer in this way.</p> <p>If a respondent indicates that the only reason they don't use this mode of transport is that they don't want or need to, then they should not be recorded as having a participation restriction/barrier.</p>		
Community, Leisure and Civic Life				
LifeOppA, LifeOppB	Record whether there are any barriers or restrictions to participating in community, leisure and civic life. (ICF code d910-d999)	<p>This approach was designed to replace a previous version, where each activity was asked about in a separate question, with a showcard indicating four possible outcomes:</p> <p>(1) I don't do this activity - and don't want to (2) I don't do this activity - but would like to do it (3) I do this activity - as much as I want to (4) I do this activity - but would like to do it more often</p> <p>The problem with this question was that people may say they don't want to do an activity precisely because of the barriers they face. That is, they have been conditioned to accept their restricted situation, their expectations have changed, and within these new parameters they do not want to do an activity.</p> <p>LifeOppA asks the respondent to think about what they would like to do in an ideal world, as an attempt to get</p>	Previous approach qualitative testing and feasibility trial. New approach pilot only.	Yes

		<p>them to think about their situation without barriers. LifeOppB asks about their current participation. Comparing answers to the two questions reveals where respondents don't currently do activities they would like to, or where they don't do activities as much as they would like. This also means we can ask about more activities with less questions.</p> <p>It is likely that many people will reveal they don't do some activities as much as they want, for example going on holiday. However, the analysis of these questions will be done at the aggregate level allowing comparisons to be made across diversity strands.</p>		
StopHol, StopFri, StopFam, StopSpor, StopCa, StopMus, StopThe, StopCine	Record various contextual factors (environmental/social barriers and personal factors) which may be contributing to restrictions to participating in community, leisure and civic life.	<p>The list of contextual factors has been designed through consultation with the RADAR reference network of disabled people. These are some of the most common reasons given by RADAR members. They have also been qualitatively and quantitatively tested.</p> <p>Health condition/disability are also included, as under the ICF, body functions and structures interact with contextual factors in the process of participation restriction. In addition, testing has shown people with impairments or health conditions will often want to answer in this way.</p> <p>If a respondent indicates that the only reason they don't use this mode of transport is that they don't want or need to, then they should not be recorded as having a participation restriction/barrier.</p>	Qualitative testing, feasibility trial and pilot.	Yes
Choice	Measure the level of choice respondents feel they have over how they spend their time.	This is intended to feed into information for ODI's independent living strategy.	Qualitative testing, feasibility trial and pilot.	No
Accessibility - The Home				

GetHome	Screen for any accessibility issues getting into rooms in the home. Indicates presence or absence of an activity limitation/participation restriction relating to moving around within the home. (ICF code d4600)	The interviewer instruction states 'with help or assistive devices if normally used'. This is because we are only interested in where a barrier currently exists. If appropriate facilitators have been brought in to make rooms accessible, for example a stairlift or a full time carer, then the restriction has been removed.	Qualitative testing, feasibility trial and pilot.	Yes
GetRoom	Record which rooms the respondent has difficulty getting into.	An earlier version of the questionnaire asked a separate question on accessibility for each room. The new version saves time although we no longer have a scale for level of difficulty for each room.	Qualitative testing, feasibility trial and pilot.	Yes
AccHome	Record various contextual factors (environmental/social barriers and personal factors) which may be contributing to restrictions to accessing rooms within the home.	The list of contextual factors has been designed through consultation with the RADAR reference network of disabled people. These are some of the most common reasons given by RADAR members. They have also been qualitatively and quantitatively tested. Health condition/disability are also included, as under the ICF, body functions and structures interact with contextual factors in the process of participation restriction. In addition, testing has shown people with impairments or health conditions will often want to answer in this way.	Qualitative testing, feasibility trial and pilot.	Yes
InOut	Screen for any accessibility issues getting in or out of the home. Indicates presence or absence of an activity limitation/participation restriction relating to moving in or out of the home. (ICF code d4600)	This was added by request from a Government Department who pointed out that we cover inside the home and outside the home, but for some people there are issues with getting out/in the home due to stairs, slopes and so on.	Pilot only	Yes
InOutWhy	Record various contextual factors (environmental/social barriers and personal factors) which may be contributing to restrictions to getting in or out of the home.	This is the same list as for AccHome.	Qualitative testing, feasibility trial and pilot.	Yes
Accessibility - Outside the home				

IntoBld, ThruBld, FacBld	Screen for any accessibility issues with buildings outside the home. Indicates presence or absence of an activity limitation/participation restriction relating to buildings outside the home. (ICF code d4600) Three questions distinguish between 1) getting into buildings, 2) moving round inside, and 3) using facilities.	Earlier versions of these questions asked about the level of difficulty accessing each building. This meant there were a lot of questions, with no distinction between getting into, moving around and using facilities.	Qualitative testing, feasibility trial and pilot.	Yes
WhichBld	Record which buildings the respondent has had difficulty getting into.	The list of buildings has been chosen through consultation with the RADAR reference network of disabled people. They have also been qualitatively and quantitatively tested.	Qualitative testing, feasibility trial and pilot.	Yes
BldAccPr	Record various contextual factors (environmental/social barriers and personal factors) which may be contributing to restrictions to accessing buildings.	The list of contextual factors has been designed through consultation with the RADAR reference network of disabled people. These are some of the most common reasons given by RADAR members. They have also been qualitatively and quantitatively tested. Health condition/disability are also included, as under the ICF, body functions and structures interact with contextual factors in the process of participation restriction. In addition, testing has shown people with impairments or health conditions will often want to answer in this way.	Qualitative testing, feasibility trial and pilot.	Yes
Services and Policies				
ServUse	Record which services the respondent has dealt with in the past 12 months.	Under the ICF, 'services, systems and policies' is not a domain of participation, rather it is a component of the environmental factors (barriers and facilitators) which contribute to participation restrictions. This section does not directly measure a participation restriction. The main reason for including this section is the	Qualitative testing, feasibility trial and pilot.	No

		usefulness of the data to Government Departments. It can also provide more detail on the reasons behind participation restrictions, for example, a respondent may be limited in the type of work they can do because they have had difficulty accessing the jobcentre, either due to the presence of a barrier or the lack of a facilitator.		
DiffHlth, DiffJust, DiffBen, DiffSpor, DiffTax	Record the level of difficulty accessing the service.	These follow up questions are only asked of those respondents who have contacted the service in question in the last 12 months. This is because we want to know about actual experiences of service use, rather than general perceptions of public services.	Qualitative testing, feasibility trial and pilot.	No
DfctHth, DfctJust, DfctBen, DfctSpor, DfctTax	Record various contextual factors (environmental/social barriers and personal factors) which may be causing difficulty accessing the service.	<p>The list of contextual factors has been designed through consultation with the RADAR reference network of disabled people. These are some of the most common reasons given by RADAR members. They have also been qualitatively and quantitatively tested.</p> <p>Health condition/disability are also included, as under the ICF, body functions and structures interact with contextual factors in the process of participation restriction. In addition, testing has shown people with impairments or health conditions will often want to answer in this way.</p>	Qualitative testing, feasibility trial and pilot.	No
Domestic Life				
Wash, Toilet, Nails, Dress, Eat, Shop, PrepMeal, Hwork, HRepair	Record various facets of activity limitation, set out in ICF chapters Self-care and Domestic life. (ICF codes d510-d599, d610-d699)	This list of activities is based on ICF items from d510 to d699. The questions are similar to a very similar set of questions was asked on the 2000 Psychiatric Morbidity Survey (a.k.a. Mental Health and Wellbeing). They are also similar to Katz's Activities of Daily Living (ADLs). Many health surveys use similar questions.	Qualitative testing, feasibility trial and pilot.	No
WhoHelp	Record who helps a respondent if they have indicated they need help with any of the activities.	The list of people has been substantially shortened since earlier versions, which were seen as too intrusive by respondents in the qualitative testing. The question asks	Qualitative testing, feasibility trial and pilot.	No

		'can I just check...' because it may be that the person needs help but is not receiving it.		
OftenHlp	Record frequency of help	Early drafts of this question asked only about frequency of help in terms of daily, weekly, monthly or less often. Testing revealed that frequency depends on need, so varies according to need. The question was subsequently reworded to refer to help when needed.	Qualitative testing, feasibility trial and pilot.	No
HelpSay	Record how often the respondent feels they have a say over the help they receive.	This is intended to feed into information for ODI's independent living strategy.	Feasibility trial and pilot.	No
Caring for Others				
CareHhld, CareLOut	Record whether the respondent gives care to anyone. A distinction is made between care within the home and care outside the home.	Questions in this section are taken from a module run on GHS.	Since these had been run before, we did not qualitatively test them. They were run on the feasibility trial and pilot.	No
CareHour	Record time spent providing care.		Feasibility trial and pilot.	No
Discrimination				
Discrim	Record whether the respondent feels they have been treated unfairly for any of the reasons on the card.	This question comes from the Northern Ireland survey (NISALD). The original question asked about 'discrimination', providing a definition which talked about unfair treatment. We no longer use the term 'discrimination' as we think people may have been treated unfairly but not want to label the experience as discrimination. There was some question over the terminology used for 'sexual orientation'.	Qualitative testing, feasibility trial and pilot.	No
DisWho	Record who discriminated against the respondent.	The list of people has been designed through consultation with the RADAR reference network of disabled people. They have also been qualitatively and quantitatively tested. However, they do not represent the most common people who discriminate against others.	Qualitative testing, feasibility trial and pilot.	No
JobAtt	Record workplace discrimination specifically because of a health	This question is a variation of a question translated from a French/Canadian survey and is specifically about	Feasibility trial and pilot.	No

	condition or disability.	workplace discrimination due to disability/health conditions. It is only asked of people currently in work who said in Discrim that they have been treated unfairly because of a health condition/disability.		
Crime				
Crim	Record experience of crime.	This question was developed based on questions from the British Crime Survey (BCS) in consultation with the Home Office. Early versions asked simply 'have you been a victim of a crime'. However, current approaches ask about specific incidents.	Feasibility trial and pilot.	No
HCrim	Record hate crime.	The definition provided comes from NISALD.	Feasibility trial and pilot.	No
HCrimYe	Record whether the hate crime was in the last 12 months.	This is for longitudinal analysis purposes.	Feasibility trial and pilot.	No
CrimTyp	Record the reasons for the hate crime.	<p>This question started life as 'Was this crime motivated by the offender's attitude to any of the following characteristics?'</p> <p>It was felt that the language used in this wording would not be understood by all respondents, particularly those with learning disabilities.</p> <p>The current wording is easier to understand, but does mean that the responses aren't, strictly speaking, valid 'reasons' for crime. However, there is a trade-off between writing questions which are theoretically and semantically correct, and writing questions which are easily understood.</p>	Feasibility trial and pilot.	No
Social Contact				
CloseNum, MeetNum, MeetOft	Record whether there are any barriers or restrictions to participating in interpersonal interactions and relationships (ICF d710-d799).		Pilot only.	Yes
PrevCont	Record various contextual factors (environmental/social barriers and		Pilot only.	Yes

	personal factors) which may be contributing to restrictions to participating in interpersonal interactions and relationships.			
DDA				
All questions	Measure DDA status.	These questions are the current standard suite of questions for estimating the population covered by the Disability Discrimination Act. DDAProg is included as those three conditions are specifically mentioned under the act, regardless of whether they are currently causing substantial difficulties.	Feasibility trial and pilot.	No
Impairments and Health Conditions				
All questions	Record the presence or absence of impairments or health conditions.	<p>This section is structured in the format of 14 screener questions, with follow up questions where appropriate. Derived variables will need to be calculated from these follow up questions to indicate whether the respondent has an impairment.</p> <p>Where help or assistive devices are normally used, the questions ask about the situation <i>with</i> this assistance. Other disability surveys ask about both with and without, however we have had to keep this section short.</p>	Qualitative testing, feasibility trial and pilot.	Yes
Benefits				
All questions	Record receipt of benefits.	These have been included due to a request from ODI and DWP. The questions are based on questions from LFS, but have been developed in consultation with DWP to include a broader range of disability related benefits.	Feasibility trial and pilot.	No
Quality of Life				
Quality, QualWhy	Encourage positive discussion and improve the sense of satisfaction respondents have at the end of the survey.	This question is based on a similar idea used on the British Household Panel Survey. Qualitative testing warned that the survey may feel too rigid and restricted, and that by not allowing respondents to express their situation, we risk leaving them disillusioned. This would ultimately impact on wave 2 response.	Pilot only.	No

		These open ended questions may add to the survey length, but the respondent can take as little or as much time as they like to answer them.		
KITE				
Consent		As with the BHPS, a decision was made not to specifically ask explicitly for consent to follow up. The Blaise questionnaire only includes a function for spontaneous refusal.		

Appendix 2: Using the ICF coding scale

The ICF uses an alphanumeric system in which the letters b, a, d and e are used to denote Body Functions, Activities and Participation, and Environmental Factors. These letters are followed by a numeric code which corresponds to components of the ICF. A qualifier can be added to a code to denote the magnitude of a problem. Without qualifiers, codes have no inherent meaning. Using the ICF codes and qualifiers may aid comparisons between other international surveys using ICF, although they are not essential to producing outputs.

Coding body functions

One qualifier indicates the extent or magnitude of impairment:

b210	This is the code for 'seeing functions'
b201.0	NO impairment in seeing functions
b201.1	MILD impairment in seeing functions
b201.2	MODERATE impairment in seeing functions
b201.3	SEVERE impairment in seeing functions
b201.4	COMPLETE impairment in seeing functions

Coding activity limitations

The ICF uses two qualifiers for these categories:

- Performance qualifier - what an individual does in his or her current environment
- Capacity qualifier - an individual's ability to execute a task or an action, without assistance.

The LOS questionnaire does not currently have questions to measure ability without assistance, so only the performance qualifier can be coded:

d330	This is the code for 'speaking'
d330.0	NO difficulty speaking
d330.1	MILD difficulty speaking
d330.2	MODERATE difficulty speaking
d330.3	SEVERE difficulty speaking
d330.4	COMPLETE difficulty speaking
d330.8	Not specified
d330.9	Not applicable

Coding participation restrictions

The ICF uses the same qualifiers for participation restrictions as for activity limitations, however most of the questions in the LOS questionnaire do not allow for a 5 point breakdown as they tend to be yes/no questions. For example, LearnLim asks whether the respondent has access to all the learning opportunities they want, rather than how much difficulty the

respondent has accessing all the learning opportunities they want. Unless the questions are changed to accommodate a severity scale, use of the ICF qualifiers are limited for this area.

Coding environmental factors

Environmental factors should be coded with reference to the relevant component of functioning. For example, if someone experiences cost as a barrier to transport, this could be coded as d4702 e1650, where d4702 is the code for 'using public motorized transportation' and e1650 is the code for 'financial assets'.